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ABSTRACT

Because women have predominated as caregivers of the elderly, very little is known about the family support systems of men who assume this role. This study, based on a national study of male caregivers, examined the availability and level of family help received by male caregivers; the closeness, allegiance, and supportiveness in their families; and the relationship between these variables and such issues as caregiver burden and the degree of affectionate reciprocity between the caregivers and the recipients of their care. The results revealed that the average male caregiver was a white, protestant, middle class, moderately well-educated, retired man who was 68 years old. Most caregivers were husbands taking care of their wives. A minority were sons caring for a parent; instances of men helping in-laws, siblings, or friends were rare. Caregivers spent many hours each day performing a broad range of caregiving tasks and had been doing so for long period of time. Although most had living children or siblings, levels of concrete assistance from relatives were uneven. Study findings have implications for gender-sensitive service delivery and suggest directions for future research on male caregivers. (Author/NB)

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# MALE CAREGIVERS OF THE ELDERLY:

# THE INTEGRITY OF THEIR FAMILY SUPPORT NETWORKS*

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**Abstract**

MALE CAREGIVERS OF THE ELDERLY:

THE INTEGRITY OF THEIR FAMILY SUPPORT NETWORKS

Because women have predominated as elder caregivers, very little is known about the family support systems of men who assume this role. Based on a national study of male elder caregivers, this article examines the availability and level of family help they received; the closeness, allegiance, and supportiveness in their families; and the relationship between these variables and such issues as caregiver burden and the degree of affectionate reciprocity between the caregivers and the recipients of their care. Study findings have implications for gender-sensitive service delivery and suggest directions for future research on this understudied population.

# MALE CAREGIVERS OF THE ELDERLY: THE INTEGRITY OF THEIR FAMILY SUPPORT NETWORKS

Although the late twentieth century family is changing dramatically, one of its characteristics--the tradition of family elder care--persistently endures. Study after study confirms that families, not formal service personnel, provide the bulk of health care and other services to the burgeoning multitude of impaired older people (Horowitz, 1985b; Horowitz and Shindelman, 1983; Shanas, 1979; Stoller, 1983; Stone et al., 1987). These studies lay to rest the popular myth that Americans have abandoned their frail elderly to nursing homes. To the contrary, 95% of old people and 90% of those who are physically impaired live at home where their spouses, adult children, or other kin care for them ("Mothers bearing," 1989).

Thanks to advances in health care and steadily declining mortality rates, the proportion of the aging population most likely to need family assistance is growing almost exponentially. Between 1960 and 1980, there was a 141% increase in the ranks of people 84 years old and older; and there will be another surge when the baby boom cohort reaches old age. From a 1980 figure of 2.3 million, the number of persons 85 and older is expected to soar to 13 million by 2040 (Longino, 1988). Given present trends, by 2080 there will be three million people between the ages of 95 and 99, and more than a million100 years old and over (U. S. Bureau of the Census, 1989).

Unless there is a revolution in public health care policy, it is unlikely that formal services will adequately assist these citizens, at least 70% of whom will require some help with routine activities of daily living

(Longino, 1988). The United States appears to be rapidly reaching its absorptive capacity to provide such formal supports. Fiscal policies spawned by the New Federalism have reduced or eliminated scores of federally funded programs previously available to the elderly and their families. Those programs that remain support short-term hospital care for acute conditions rather than home care for the lingering chronic illnesses that plague the oldest old (Hooyman and Lustbader, 1986; Moore, 1983). Returned by DRGs "quicker and sicker" to the laps of their families, these frail elderly people require high levels of supportive health care (Fischer and Eustis, 1988; Kaye, 1988).

And the available pool of family members who must try to orchestrate this care is shrinking. A declining birthrate will leave prospective caregivers in short supply. At the beginning of the century, there were almost three women 35 to 44 years old for every widow and divorcee 55 years or older. By the mid-1980s this ratio had narrowed to 1.32 women in the 35 to 44 age range for every widowed or divorced woman 55 or older (Sherman et al., 1988).

Moreover, in most instances "family caregiving" means care by one principal relative (Horowitz and Dobrof, 1982; Johnson and Catalano, 1983; Young and Kahana, 1989). The levels of assistance these lone caregivers receive from other relatives is at best uneven, and, at worst, non-existent. In one sample of 753 noninstitutionalized elders, for example, helping networks were either empty or consisted of one other helper. Only 5% of this sample reported more than one other assistant (Stoller and Earl, 1983). As elder care recipients with chronic conditions become more impaired and require more assistance, caregiver stress levels climb (Stoller and Pugliesi, 1989), and the number of available helpers tends to

decline (Stoller, 1985). Just as in the case of early parent care of dependent infants, the care of the highly dependent, incapacitated elder tends to become a dyadic enterprise.

The analogy between infant care and elder care is apt in light of the reality that, in most instances, primary elder caregivers--like caregivers of infants--are women. As an elderly person in the family begins to need help, an unpaid female relative, usually a wife, adult daughter, or daughter-in-law, steps into the primary caregiving role (Brody, 1981, 1985, 1986; Horowitz, 1985a, 1985b; Sherman et al., 1988; Stone et al., 1987). Women constitute two-thirds to three-quarters of elder caregivers in most research samples (Wood, 1987). They tend to live closer to their families of origin, have more frequent contact with them, and feel closer emotionally to them than men do (Troll et al., 1979).

Western sex role socialization aims young women toward caregiving by encouraging their activities at the domestic center of the family and preparing them for nurturing roles across the life cycle (Block, 1984). Women are expected to be kinkeepers (DiLeonardo, 1987), and, until recently, their primary roles as homemakers have afforded them more of the flexible time required for caregiving than men have had (Horowitz, 1985b). The exploitation of their apparent availability has led many women into careers of caregiving that begin with child care, often include care of an ailing spouse, and end with elder care. Today the average woman spends 17 years of her life taking care of children and 18 years helping aged parents ("Mothers bearing," 1989).

But, poised on the threshold of the twenty-first century, we can no longer assume that women will be available or willing to devote their middle and later years to elder care. The trend toward smaller families

portends fewer female offspring to assume caregiving duties. Moreover, among women aged 45 to 64--those "women in the middle" (Brody, 1981) most likely to be entangled in a web of competing demands from children, husbands, and elderly kin--64% are now in the labor force (Schick, 1986). In addition to financial imperatives that send them to work outside the home, gains from the women's movement permit women to consider professional alternatives to careers of caregiving. Distressingly, many try to do it all, placing themselves at risk for role overload and probable burnout.

As women become less available, it is likely that men will be called on increasingly to absorb more responsibility for the care of elderly relatives. Although daughters and daughters-in-law continue to shoulder most of the load, many sons are primary caregivers for aging parents (Brody, 1986; Horowitz, 1985b; Montgomery and Kamo, 1987; Rathbone-McCuan and Coward, 1985; Stoller, 1983). The caregiving gender gap narrows substantially when it comes to spouse caregivers (Pruchno and Resch, 1989). In part because more women than men are diagnosed as having Alzheimer's disease, many husbands provide primary care to their ailing wives (Davies et al., 1986; Fitting and Rabins, 1985; Fitting et al., 1986; Hlavaty, 1986; Motenko, 1988; Vinick, 1984; Zarit et al., 1986).

Most studies suggest that male caregivers are more apt to receive family assistance than female caregivers are. This is likely to be especially true when comparing sons and daughters (Hlavaty, 1986; Horowitz, 1985a). But the 1982 national Informal Caregivers' Survey found that 50% of the husbands who responded were caring for impaired wives with neither formal nor informal help (Stone et al., 1987). More recently, Barusch and Spaid (1989) found no significant differences

between husband and wife caregivers in the levels of family support they received. The subjects in Vinick's (1984) retrospective study of men who had cared for a disabled spouse spoke of help from some formal services but did not mention family help. Motenko (1988:118) concluded that some of the male spouse caregivers in her ethnographic study were receiving assistance from their children that was "frequently inappropriate, rarely generous, and sometimes rejected." These men preferred to remain in control and wanted support for, rather than time away from, their primary caregiving role. Clearly, the data gathered to date send mixed messages. There is much to learn about the extent and dynamics of family support for male caregivers.

## Methods

Sample

The findings reported here derive from mail survey questionnaires completed by a national convenience sample of 152 leaders of caregiver support groups and 148 male participants in these groups. (Up to two men were invited to respond from each group.) This sample was gathered from national directories maintained by the National Council on Aging, Inc., and Children of Aging Parents, Inc., a nation-wide networking organization that offers start-up assistance to caregiver support groups. Adjusted for maximum allowable protocol returns, response rates were 65.2% for the support group leaders and 64.6% for the male participants.

It is important to note that generalizability from this sample to all male caregivers is limited by a self-selection factor. Because these men had joined caregiver support groups, they may not be representatitive of all caregivers, many of whom "go it alone" without benefit of such formal services. Intuitively it would seem that those willing to use support

groups would be more likely to use family assistance; or perhaps men using such groups do so in the absence of family help. The absence of a control group of men not attending support groups makes it impossible to examine such variables.

Measurement

The structured self-report questionnaire administered to the male caregivers consisted of 74 questions about the tasks they performed; the quality of their relationships with their care recipients and families; their stresses, burdens, and coping strategies; gender factors in caregiving; and the extent to which self help, family aid, and formal support programs were helpful to them. The group leaders responded on a similar instrument to 65 questions about the structure, function, and procedures of their groups and about their perceptions of the nature of the family supports available to men in their groups. Findings presented here focus on dimensions of the family support network.

Individual questions to which caregivers and leaders responded on a Likert-type scale assessed the men's perceptions of their families' attitudes toward their help, the quality of relatives' relationship to the care recipients, and the frequency with which families helped out. Two indices were developed to measure levels of affectionate reciprocity in caregiving. On the Recipient Affection Index, caregivers rated the frequency with which their care recipients initiated affectionate behaviors (on a 5-point scale ranging from "rarely or never" to "almost always"); and on the Provider Affection Index, caregivers used the same scale to rate the frequency with which they initiated affection. Reliability coefficients (standardized item alphas) for these indices were .88 and .83, respectively.

In addition to these original questions and indices, a number of previously developed instruments, modified when necessary, were employed. Pertinent here are (1) the 8-item Familism Index, developed by Heller (1970) to assess the strength of relationship and allegiance among members of the caregiver's family (reliability coefficient = .80); (2) the Family Function Index, a modified version of the Family APGAR developed by Smilkstein (1978) to gauge the male caregiver's level of satisfaction with the concern expressed for him by the elder care recipient (reliability coefficient = .85); (3) the Quality of Relationship Index, a shortened and modified version of the Index of Marital Satisfaction developed by Hudson (1982) to assess the degree of satisfaction in intimate relationships (reliability coefficient = .71); and (4) a shortened version of Zarit's, Reever's, and Bach-Peterson's (1980) Burden Scale designed to measure caregiver stress and strain (reliability coefficient = .87). Each of these indices employs a Likert-type rating scale.

## Results

### A Profile of Male Caregivers and Recipients

The average male caregiver in the study was a white (96%), protestant (64%), middle class, moderately well-educated, retired (72%) man who was 68 years old. Most caregivers (68%) were husbands taking care of their wives; only a minority of the sample were sons caring for mothers (12%) or fathers (6%). Instances of men helping in-laws, siblings, or friends were rare. Sixty-five percent of the men were living with the recipients of their care and managing relatively well financially. Ninety-five percent had been in a caregiving role for more than a year, with nearly a third (32.3%) reporting caregiving for 5 years or longer. More than half (51.4%) provided in excess of 60 hours of caregiving during an

average week. These men were performing the broad range of social support, instrumental, case management, and functional tasks associated with elder caregiving, from companionship and emotional support to personal care.

The Family Support Network

The men in this study assumed a central caregiving role although there were other potential family caregivers available. Nine out of ten (87.8%) had living children, with almost three-quarters (72.2%) reporting two or more. Half (50.8%) had living brothers and 62% had sisters.

Table 1 reveals that, despite these family contexts, the majority of respondents viewed themselves as primary caregivers. More than a third were sole care providers, and only relatively few reported receiving assistance from more than two family helpers. Levels of family assistance were uneven, with a slight majority of respondents receiving such help only "seldom" or "rarely." Only just over a fifth reported receiving very frequent assistance.

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Table 1 About Here

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Unexpectedly, subjects mentioned sons of recipients more frequently than daughters (20.6% vs. 18.5%) as supplementary sources of aid. Others assisting the men were, in descending order, spouses, daughters-in-law, sisters, sons-in-law, granddaughters, grandsons, and neices.

Only just over a third (35.2%) of the caregivers, however, believed there were people in the family who should be helping out but were not doing so. Asked to designate these potential helpers, a third of this group cited daughters and almost 30% cited sons. Siblings and daughters-in-law

were mentioned with moderate frequency, and grandchildren and nephews were mentioned least often.

Very few factors in the caregivers' situations appeared to influence the amount of help other family members provided. Only the decreased mental health impairment of the recipient (Pearson's $r = -.18$), his or her increased behavior problems ($r = .15$, $p < .05$), and, to a lesser degree, poor physical health in the caregiver ($r = -.15$, $p < .05$) were associated with increases in family assistance. And these associations, though statistically significant, were weak. Neither the caregiver's age, his mental health, nor his level of functional impairment was associated with increased family help. Moreover, there was a slight tendency for the absolute number of family members providing supplemental assistance to decline over time ($r = -.16$, $p < .05$).

Support Group Leaders' Views of Male Caregivers' Family Support Networks

Based on the experience of 585 male participants in their support groups, the leaders' views of caregiver family networks mirrored those of the men themselves. As seen in Table 2, they believed that male participants were unlikely to have more than one additional person to help them with caregiving; and about two in ten of the leaders believed no one else was available.

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Table 2 About Here

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Almost 63% of the leaders believed that none of the men in their groups felt that there were other people in the family network who should be providing care (compared to 65% of the men themselves). Furthermore, 59% reported that none of their male participants believed they carried

too much of the burden of care; less than a third believed that several of the men in their group felt overburdened.

The Relationship Context

The uneven levels of family assistance as well as the caregivers' relatively modest expectations of such help did not appear to stem from a lack of perceived family closeness. Though the overall level of allegiance among relatives as measured by the Familism Index was only moderate, most of the men believed their families to be "very supportive" (65%) or "somewhat supportive" (21%) of the job they were doing. Perceptions of the support group leaders, however, moderate this glowing view; only 32% believed that men in their groups would view families' attitudes as "very supportive," while 58% thought that men would rate family attitude as "somewhat supportive." Still, the overall picture is positive; and leaders believed the quality of caregivers' family relationships were "good" (70%) to "excellent" (17%).

It is interesting that this positive view emerged even though nearly half the men (47%) reported that their families helped them out in concrete ways only "seldom" or "rarely." It appears that their sense of support was more important to them than actual assistance. Nevertheless, as seen in Table 3, ratings of the frequency with which relatives helped out were positively and strongly correlated with the men's ratings of the degree of family allegiance (as measured by the Familism Index), their view of their families' attitudes toward the quality of their help, and their assessment of the nature of the families' relationship to recipients.

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Table 3 About Here

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In addition, there were moderate associations--all significant at the $p < .001$ level--between these family relationship indices and lower levels of burden reported by the men. These indices were unrelated to the men's assessment of the frequency with which their care recipients initiated affectionate behaviors for them (Recipient Affection Index); and neither family allegiance nor the families' attitude toward the quality of care the men provided was associated with the frequency with which men reported initiating affection with recipients (Provider Affection Index). But there was a statistically significant positive relationship between the men's ratings of the quality of the families' relationships to the care recipients and the frequency with which they themselves initiated affectionate behavior. Predictably, the men's views of the quality of the families' relationships with recipients were also positively associated with their ratings of the quality of their own relationships with recipients (Quality of Relationship Index). Weaker but statistically significant associations appeared between the men's level of satisfaction with the concern expressed for them by elder care recipients (Family Function Index) and their ratings of family allegiance, their families' attitudes toward the quality of care they were providing, and the nature of their families' relationships with recipients.

As caregiver support group leaders saw it, the better the overall relationship existing between male caregivers and their families, the more there was affective reciprocity between caregivers and recipients ($r = -.31$, $p < .001$). As could be expected, the worse their assessment of overall family relationships, the more the leaders believed that male caregivers felt others should be helping out but were not ($r = .35$, $p < .001$) and that they were carrying too much of the burden of care ($r = .36$,

$p < .001$). Similarly, support group leaders' ratings suggest that the more male caregivers felt supported by their families, the less likely they were apt to feel they were carrying too much of the burden ($r = -.17$, $p < .05$).

Clearly, male caregivers' experiences of providing elder care to relatives were more positive when they did so in contexts where families were closely allied, supportive, and had a good relationship with the recipient. In addition, perceived family allegiance was associated with the men's feelings of competence in their caregiving ($r = .33$, $p < .01$) and with their level of satisfaction with the tasks they were performing ($r = .39$, $p < .05$). Interestingly, the frequency with which family members helped out was not related to levels of burden ($r = .02$, $p > .05$). It is possible that a positive family attitude made more difference in reducing feelings of burden than did literal helping efforts.

## Discussion

Profile data on this sample of men taking care of an elderly relative suggest that they were on the front lines of primary caregiving. These caregivers, most of them white, middle-class, retired men looking after a wife with Alzheimer's disease, spent many hours a day performing the broad range of caregiving tasks and had been doing so for long periods of time. Though most had living children or siblings, levels of concrete assistance from relatives were uneven. These findings are in line with those of Stoller and Earl (1983) who found caregiver family networks for their large sample of caregivers to be either non-existent or quite restricted. Also, our finding that the absolute number of relatives providing care declined over time lends support to Stoller's (1985) conclusion that, as caregiving stretches into chronicity, it becomes increasingly a one-to-one arrangement.

In instances where children were assisting, sons were doing so more frequently than daughters. This finding, although surprising in terms of what we know about gender and caregiving, echoes the pattern reported by Rathbone-McCuan and Coward (1985) whose sample of 900 non-institutionalized elders were also receiving more help from sons than from daughters. It is possible, of course, that sons were assisting only in the absence of daughters or other available relatives, as was the case in Horowitz's (1985b) sample. Barusch and Spaid (1989), however, found that husband and wife caregivers in their sample tended to turn to children of the same gender for support.

The majority of the men in our sample identified themselves as primary caregivers even though most had living children or siblings. The finding that relatively few believed there were other family members who should be helping but were not doing so may mean that many of the men did not mind "going it alone." Or it is possible that they were reluctant to seek help from families, living out the traditional gender imperative that they should bear-up, keep a "stiff upper lip," and be, at all costs, self-sufficient. Findings from other research, however, suggest that when spouses are primary caregivers, the likelihood of supplementary assistance declines (Johnson, 1983), especially for husbands (Tennstedt et al., 1989). Since the majority of caregivers in this sample were men caring for wives, the norm of spousal reciprocity may have overridden gender variables in explaining their primary status and low expectations of family help. When relatives did step in, they did so only in relation to impairment in the caregiver's health or in instances of poor mental health or behavior problems in the care recipient.

In the face of such unevenness in both family assistance and the caregivers' expressed wishes for it, it is interesting that those with available relatives saw them as strongly allied with the family, close to the recipients of their care, and generally supportive of the job they were doing, a perception that was mirrored by leaders of the support groups they were in. And these relationship variables were associated with an increased frequency of concrete assistance. This analysis does not allow us to disentangle the likely interactions among these variables. Nevertheless, although we cannot determine the direction of influence, it is clear that higher levels of family assistance were related to strongly allied, close, and supportive family contexts.

These subjective, contextual variables also appeared to ameliorate feelings of burden in the men--moreso than did the actual frequency of concrete help, which had virtually no effect. It would seem that, as long as male caregivers feel supported by their families, they can go on alone or with minimal help and can sustain affection for the recipients of their care. It is possible, of course, that these respondents were giving care from a traditional male "stoic-intellectual" posture that kept them distanced from the guilt, depression, and other burdensome emotional strains to which women are believed to be more subject (Davies et al., 1986). They may have been enduring the stresses of elder caregiving because it was the right thing to do, responding to what Gilligan (1982) refers to as an ethic of justice characteristic of male moral development.

But recent qualitative research suggests the possibility of a more complex picture of men's experience of elder caregiving that may also help explain this study's findings related to burden. From her ethnography of men caring for their disabled wives, Motenko (1988) found that the

caregiving tasks themselves did not appear to be burdensome to the men; it was the loss through decline in the quality of the spousal relationship that was most stressful. In fact, these caregivers appeared to view their tasks as labors of love which brought them a sense of pride and competence. Caregiving appeared to provide the men with a sense of affective connectedness that helped them preserve aspects of a meaningful and close relationship with their wives. They appeared to be motivated by an ethic of caring (Gilligan, 1982) that provided them considerable gratification. This appears to have been the case with many subjects in the present study who, when asked what they found most satisfying about their caregiving roles, cited feelings of love and commitment. As one respondent put it, "She has been a wonderful wife and mother, and I love her deeply and enjoy demonstrating my love by taking care." Perhaps such men, like those in the study by Fitting and associates (1986), have found a new role in caregiving that, rather than being burdensome, afforded them the chance to express previously suppressed nurturant strivings.

Those working with families of male caregivers need to consider the variety of meanings caregiving may hold for them. If, as this study suggests, expressions of family solidarity and allegiance are more important than actual helping efforts in reducing burden and increasing feelings of competence and satisfaction, relatives can be helped to shape patterns of assistance in ways that support rather than replace men's caregiving efforts. The husbands in Motenko's (1988) sample, for example, welcomed their children's companionship and the chance for brief periods of rest; but they felt that other offers of help--such as staying with the care recipient so that they could go out to the movies--were inappropriate

and unhelpful. Rather than respite, they desired ongoing ancillary support from others that enabled them to continue in their primary roles. Like the men in Miller's qualitative study (1987), they wanted to remain in control.

Hasselkus (1988) emphasizes the importance of studying and understanding the feelings, values, and other subjective and contextual factors that comprise the invisible work of caregiving. This invisible work may mean different things to male and female caregivers and may call for varying levels of family support. To tease out these nuances in the meaning of caregiving, future research should include qualitative design elements. Also, efforts should be made to include cohorts of male caregivers who are not members of support groups. Not only may such men may be receiving more support from their families than the caregivers in this sample, they may feel quite differently about it. More distressing is the possibility that many male caregivers are providing caregiving in the absence of either emotional or concrete support. As families continue to change and as their patterns of assistance to their elderly relatives shift, it will become increasingly crucial to learn more about how to assist them.

Table 1

Male Caregivers' Assessment of the Structure of the Family Support Network

| | N | % |
|---|---|---|
| Level of Caregiving Responsibility | | |
| Primary/Major | 126 | 87.5 |
| Secondary | 18 | 12.5 |
| Total | 144 | 100.0 |
| Number of Persons Sharing Caregiving Responsibility | | |
| None | 54 | 35.6 |
| One | 30 | 19.7 |
| Two | 37 | 24.3 |
| Three | 10 | 6.6 |
| Four | 10 | 6.6 |
| Five or more | 11 | 7.2 |
| Total | 152 | 100.0 |
| Frequency of Family Assistance in Caregiving | | |
| Very Often | 33 | 22.8 |
| Sometimes | 35 | 24.1 |
| Seldom | 46 | 31.7 |
| Rarely/Never | 31 | 21.4 |
| Total | 145 | 100.0 |

Table 2

Support Group Leaders' Perceptions of the Characteristics of Participants' Support Network

| | N | % |
|---|---|---|
| **Other People Available to Assist Male Caregiver** | | |
| None | 19 | 18.6 |
| One | 48 | 47.1 |
| Two | 24 | 23.5 |
| Three | 8 | 7.8 |
| Four | 2 | 2.0 |
| Five | 1 | 1.0 |
| Total | 102 | 100.0 |
| **Male Caregivers Who Feel Others Should Provide Care** | | |
| None | 77 | 62.7 |
| Several | 40 | 32.5 |
| Most | 3 | 2.4 |
| All | 3 | 2.4 |
| Total | 123 | 100.0 |

Table 2 (continued)

| Male Caregivers Who Feel They Carry Too Much Burden | | |
|---|---|---|
| None | 72 | 59.0 |
| Several | 40 | 32.8 |
| Most | 5 | 4.1 |
| All | 5 | 4.1 |
| Total | 122 | 100.0 |

Table 3

Pearson's Correlations Between Selected Caregiving Relationship Variables

| | Familism Index | Family Attutide Toward Caregiver's Help | Family's Relationship to Recipient |
|---|---|---|---|
| Frequency of Assistance | .63*** | .49*** | .53*** |
| Burden Index | -.28*** | -.27*** | -.32*** |
| Recipient Affection Index | .09 | .09 | .09 |
| Provider Affection Index | .17 | .13 | .30*** |
| Quality of Relationship Index | .15 | .12 | .28*** |
| Family Function Index | .23** | .17* | .21** |

*p < .05

**p < .01

***p < .001

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